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## House Ways and Means Subcommittee on Health Implementation of Health Insurance Exchanges and Related Provisions Testimony for the Record of: Mark Velleca, MD, PhD, Chief Policy and Advocacy Officer The Leukemia and Lymphoma Society September 12, 2012

Chairman Herger, Ranking Member Stark, Members of the Subcommittee, thank you for the opportunity to submit a statement for the record on the implementation of the health insurance exchange. The Leukemia & Lymphoma Society (LLS) appreciates the opportunity to provide our recommendations, particularly on the implementation of the federal Essential Health Benefits (EHB) benchmark plan for use in the individual and small group insurance markets. LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services. The mission of LLS is to cure leukemia, lymphoma, Hodgkin's disease and myeloma and improve the quality of life of patients and their families.

LLS is committed to ensuring access to and compliance with the most appropriate, evidence-based treatments for all blood cancer patients. Treating blood cancers involves accessing a complex set of health care services including diagnostic tests, chemo and radiation therapy, prescription drugs, and cancer treatment planning, among others. These long-term treatment plans often put patients at great financial risk due to the cost sharing burdens associated with care, even if they are insured.

Blood cancer patients and survivors who are currently uninsured and underinsured, are among those who stand to benefit greatly from the establishment of both the state-level and federal Health Exchanges. We commend those states who have progressed significantly in implementation of their state exchanges, as well as those which have demonstrated a commitment to meeting federal deadlines for implementation of health reform. After much anticipation, the U.S. Department of Health and Human Services (HHS) released a bulletin, on December 16, 2011, to provide guidance to states when determining the EHBs for state health exchanges, the small group market inside and outside the exchange, benchmarks for Medicaid and Basic Health Programs.

Instead of providing a detailed list of criteria and services that states must cover in 2014, the bulletin was vague, leaving in depth coverage decisions to states, proposing unnecessary flexibility for insurers, and creating confusion on how state policymakers move forward. This lack of clarity from HHS will place an undue burden upon states, and ultimately upon the patients we represent. We hope that HHS will soon provide more clarity in order to ensure continued progress in those states that are committed to implementing the Affordable Care Act. Furthermore, clarifying guidance from HHS could potentially encourage states that are currently undecided on exchange implementation.



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One of the most important next steps for states and the federal government is to establish a comprehensive EHB package of health care services, both inside and outside of the exchanges. As you are aware, to determine what services will be included in the EHB, states must choose from ten benchmark plans. Unless states provide affordable access to comprehensive care, the promise of meaningful access to quality, coordinated cancer care will not become reality for patients or survivors. If an EHB package leans too heavily toward maximizing flexibility at the expense of ensuring patient access to comprehensive and quality cancer care, blood cancer patients may find themselves with insurance that is inadequate and unable to meet their health care needs, while being saddled with crippling financial responsibilities.

LLS believes that states and the federal government must take a comprehensive approach when setting the standard for the EHB package. To that end, LLS supports a set of recommendations that ensures access, quality and affordability for blood cancer patients. These recommendations focus on three key principles:

- 1. A meaningful prescription drug benefit that is comprehensive, affordable and enables access to the most effective, evidence-based drug therapies that are tailored to the patient's needs;
- 2. Access to specialists, procedures and technologies for needed diagnostic and treatment services; and
- 3. Coverage for comprehensive cancer planning as well as palliative and end of life care.

Policymakers must take a comprehensive approach when setting the standard for the Health Exchange and the EHB package. Creating a benchmark plan that is broad in scope, while offering affordable coverage, is key. Because blood cancers are generally not preventable, we urge HHS to encourage the implementation of robust plans with sufficient benefits to ensure coverage for diagnosis, care planning and treatment.

LLS strongly encourages HHS and states to adopt the following recommendations as part of their benchmark plans:

- 1. A prescription drug benefit with full coverage of the six protected classes, including multiple drugs in a range of therapeutic categories, as defined in the Medicare Part D program, and a patient appeals process.
- 2. Independent Pharmacy and Therapeutic (P&T) Committees that review the drugs included on a Plan's formularies, as well as the utilization management requirements for such drugs, and consideration of newly approved treatments and indications for inclusion in formularies within certain timeframes, such as those required under Part D.
- 3. A mechanism for incorporating new therapeutic categories or classes in order to protect patients' access to innovative therapies as they become available.
- 4. Equal treatment of out-of-pocket expenses to patients receiving intravenous, injectable, and/or orally administered anti-cancer therapies.



- 5. Drugs and biologics, both physician & self-administered and off-label uses, according to the evidencebased standards utilized in the Medicare program.
- 6. Affordable access to procedures standard to the treatment of blood cancers, including bone marrow and cord blood transplants and radiation therapy.
- 7. Allow cancer patients to seek treatment at National Cancer Institute (NCI) Cancer Centers or any other out of network provider.
- 8. An external appeals process for cancer patients denied coverage of "routine patient care" in cancer clinical trials until the federal requirement for coverage of routine patient care in clinical trials takes effect in 2014.
- 9. Diagnostic services using all available evidence-based technologies.
- 10. Individual, comprehensive cancer planning that is communicated by health care professionals both orally & in written form.
- 11. Palliative & hospice care.

We greatly appreciate your consideration of our recommendations. We would welcome the opportunity to discuss our recommendations further, or answer any questions you may have.